



# Washington State Core Indicators Review Panel Results

Washington State Developmental Disabilities Council  
January 2004

## Introduction

The Developmental Disabilities Council convened a panel comprised of self-advocates, family members of persons with developmental disabilities and community providers to review the results of the three adult Core Indicators surveys done in Washington State. The Core Indicators is a national study that assesses performance and outcome indicators for state developmental disabilities service systems. The Washington State Core Indicators survey participants were selected from the caseload of the Division of Developmental Disabilities. Persons with developmental disabilities and their families were asked about the services they received through the Division.

Reviewing Washington State and national data, the panel worked to develop systems change recommendations to the Developmental Disabilities Council and the Division of Developmental Disabilities. The panel met three times between October and December 2003.

After close examination of the data from the three surveys, the group identified three general areas for improvement:

- ☒ Communication
- ☒ Systems/Values
- ☒ Funding

The committee also made recommendations in other areas.

Under each identified area, there are recommended strategies. Strategies in each area are in rank-order, with the highest-ranking recommendations listed first. Each recommendation includes reference to the supporting data as well as the additional input received from the committee members. For ease in reading, surveys are numerically described in the report while detailed information is provided in Appendix A.

More detailed information about the Core Indicators Surveys and the panel members is also listed in Appendix A.

## Committee Recommendations

### Communication

**1. We recommend the Division improve the distribution of information to case managers and persons with developmental disabilities and their families and caregivers. Currently, high caseload, high staff turnover and inadequate training result in little or no information regarding available service options being provided to persons with developmental disabilities and their families.**

- ☒ Information systems are lagging (case managers). (Survey 3)
- ☒ Only 2.7% of persons with developmental disabilities own their own home. (Survey 1)
- ☒ Need to keep family informed/involved in the person with developmental disabilities' life. (Survey 2)
- ☒ Families need more support. Parents need to know more about other support services, including other parents. (Survey 3)
- ☒ Washington lags behind the national average in family participation and knowledge about fiscal (cost of) services. (Survey 3)
- ☒ People's perception of control is limited by their knowledge of "other resources". (Survey 3)

**2. We recommend developing a way for persons with developmental disabilities, their families and others to access information directly to increase their ability to make knowledgeable choices. This should include information about connecting to local communities and other families. In the current developmental disabilities system, information is only available through a case manager. The quality of information depends on the knowledge and communication ability of the case manager.**

- ☒ Information is only available through a case manager. There is no way to independently get information.

**3. We recommend the Division's Grievance Policy and Procedure be clearly explained and readily available to people in a variety of means, including availability on the Internet.**

- ☒ Why were self-advocates not asked about grievance procedure policies? (Survey 1)
- ☒ Only 35% of people were informed (knew about) the grievance policy. 44% didn't know. (Survey 2)
- ☒ Lack of satisfaction with how grievances are being handled. (Survey 2)

- ☒ Number of families knowing about the grievance policy is very low. 58.6% of families reported that they had not been informed of the Division's grievance policy. (Survey 3)

**4. *We recommend that information about non-traditional services be shared with families so they can better provide for their family member with developmental disabilities.***

- ☒ Customers are not using services such as a broker, fiscal intermediary, or micro-board, because people don't even know about available services. How do you know you have a choice, if you don't know about the options? (Survey 1)

## Systems/Values

---

**1. *We recommend increased choice and control of services for persons with developmental disabilities and their families. This should include choice in staff, activities and services. Persons with developmental disabilities and their families want the opportunity to exercise more choice in the services they receive.***

- ☒ Ability to choose is lower than national average and lower than in 2002. This includes choice in staff, where to go, access, schedules, whom the self-advocate lives with, case management and day programs. (Survey 1)
- ☒ Employment and day programs were a low choice area. Significant numbers didn't get to consider employment options and have a choice. However, 87% said they "like" working or day activity and 94% say staff are "nice". (Survey 1)
- ☒ No control over the hiring and firing of staff or employment choices. 84% say they are fine with them. (Survey 2)
- ☒ Families need more choice and control over services. Washington State families have less ability to choose the support workers that work with their family than the national average. (Survey 3)
- ☒ Questions around self-advocacy efforts do not seem to reflect participants having a clear understanding of what self-advocacy is. How can they respond accurately with inadequate information? (Survey 1)

**2. *We recommend the Division continue to survey and seek input from their customers to improve service quality.***

- ☒ There needs to be continual assessment and research to help guide policymaking. Need to continue to allocate funding for these activities. (Survey 3)

**3. *We recommend the Division continue to recognize the value of community inclusion in the lives of persons with developmental disabilities and their families.***

- ☒ Recreation and day activities are meeting expectations. (Survey 1)
- ☒ Religious service participation seems to reflect choice. (Survey 1)
- ☒ Survey seems to show that natural supports and community activities (shopping, related services) are more satisfying - community inclusion. (Survey 1)

**4. *We recommend the Division work to address the problem of access health care for persons with developmental disabilities and investigate the reason why a higher number of persons with developmental disabilities are on psychotropic drugs in Washington State than the national average.***

- ☒ Lack of dental care and female care (lower than the national average). (Survey 1)
- ☒ Higher number of people on psychotropic drugs than national average. (Survey 3)

**5. *We recommend a better definition of the role and nature of day programs (non-employment activities) for adults with developmental disabilities.***

- ☒ The continued high level of unemployment for persons with developmental disabilities increases the urgency of focusing on the structure and quality of day programs. (Survey 3)

**6. *We recommend that services provided by the Division, contractors and providers be culturally and linguistically appropriate.***

- ☒ Low numbers of clients are able to receive services in their primary language (other than English) than the national average. There is low availability of staff that can speak in families' preferred language. (Survey 3)
- ☒ There is a consistent under-representation of Latino and other ethnic populations. Low numbers of clients receive services in primary language (other than English). (Survey 1)
- ☒ Lower number of staff that speak language of ethnic population. DDD contractors and providers. (Survey 3)

## Funding

---

**1. *We recommend improving case management services by decreasing case manager caseload and providing case managers adequate training and support. In addition, we recommend a review of the case manager job***

***functions to ensure that case managers spend their time in activities that provide the most benefit to customers and taxpayers. This should provide an end result of reduced staff turnover, increased case manager competency, a demonstrated value of client self-determination of services and the provision of services in a culturally and linguistically appropriate manner.***

- ☒ Case managers are older and working with an older model and there's a gap in supporting the younger consumers who have a higher expectation around choice and independence. (Survey 1)
- ☒ System is slow in moving towards consumers who want to exercise self-determination/choice (Survey 1)
- ☒ Case managers don't ask what the consumer wants (49%) (Case mgr. Ratio) (Survey 1)
- ☒ Washington staff less knowledgeable and effective than the national average. Washington lagging behind. (Survey 3)
- ☒ Case managers have high case loads which results in poor distribution of information regarding services, etc. (Survey 1)
- ☒ Changes in case manager high. (Survey 3)

***2. We recommend improving the crisis response for individuals with developmental disabilities and their families in an emergency situation.***

- ☒ Help in emergency situations (DDD) very low number said yes. ½ didn't apply for help, and ½ of those who did, said they didn't get help. (Survey 3)
- ☒ Only 15.9% get help right away in an emergency situation. (Survey 3)

***3. We recommend increased funding, availability and creative options for in-home support and respite care.***

- ☒ Lack of respite care. (Survey 1)
- ☒ Numbers not receiving in-home support (71.7%) is too high. (Survey 3)
- ☒ Numbers not receiving respite (61.9%) and other DSHS services (75.9%) is too high. (Survey 3)

***4. We recommend increased availability and options for funding, so all families are able to meet the daily and emergency needs of the family member with developmental disabilities.***

- ☒ 76% of customers don't get what they need. This number has more than doubled since 2000. (Survey 1).
- ☒ Low numbers indicate that people aren't accessing services well. (Survey 2)
- ☒ Services at every level are too low to help families. Not one family said they could get by with less services. (Survey 3)
- ☒ Families need to be connected to local resources before they have an emergent need.

- ☑ Case managers who give assistance when asked is only 53%. (Survey 3)
- ☑ Few people saying services are “just right”. (Survey 3)
- ☑ 52% say needs are being met. Washington State ranked lowest of states surveyed for access to services and supports. (Survey 3)

**5. *We recommend increased availability and service options for employment. Low numbers of families involved in employment/day program. Lower than national average.***

- ☑ Parents value provider’s reputation in employment over wages. (Survey 3)
- ☑ Overall happy (70%). Overall satisfied with services they do receive. (Survey 2)
- ☑ Questions 61 and 62 – Lack of day program causes stress (70%). Lack of day programs causes severe stress (40.7%). (Survey 3)
- ☑ Day employment and supports provided by the state of Washington are significantly less than the national average. (Survey 3)
- ☑ Studies continue to show that those with severe disabilities have an approximate 75% unemployment rate. (U.S. VCU-RRTC on Supported Employment, 1997)

**6. *We recommend increased funding, availability and options for residential supports.***

- ☑ DSHS provided residential supports “just right” has gone from 76% in 2000 to 20% in 2002. Why are numbers that same for employment/day supports and others went down? Are we regressing? (Survey 2)

## Other Findings

**1. *We recommend the Department review the survey methodology to determine if improvements in survey construction can be made. The large percentage of no and unclear answers, along with a high degree of inconsistent answers, make the validity of the survey results questionable.***

- ☑ A lot of no/unclears (why). Questions around choice were phrased oddly, shows an increase in choice over 2000. (Survey 1)
- ☑ Questions #24 and #25 in the survey show that respondents didn’t give consistent answers (80%). Why such high numbers and what could be done differently to lower this number? (Survey 1)
- ☑ How can survey be considered accurate (Questions 24 & 25) if so many people didn’t understand questions or answer consistently? (Survey 1)
- ☑ Participation in self-advocacy- questions how they were asked this question. Ask would you like to go? Recommend a clarifying question under this question.

## Appendix A: Reviewed Material and Panel Composition

In developing their recommendations, the panel reviewed the data collected through surveys done in Washington State under the National Core Indicator's Project. More detailed information can be found on each survey:

### **Survey 1:**

Consumer Final: Survey Final Report 2001-2002 Data (Phase IV)

Available online at:

[http://www.hsri.org/docs/786\\_P4\\_Consumer2002final.pdf](http://www.hsri.org/docs/786_P4_Consumer2002final.pdf)

Washington State Core Indicators Consumer Survey Data

Available online at:

[http://depts.washington.edu/cdpr/docs/ConsumerSurvey\\_2002\\_Comparisons.pdf](http://depts.washington.edu/cdpr/docs/ConsumerSurvey_2002_Comparisons.pdf)

### **Survey 2:**

Family Guardian Survey Final Report

Available online at:

[http://www.hsri.org/docs/786\\_P4\\_FGS2002final.pdf](http://www.hsri.org/docs/786_P4_FGS2002final.pdf)

Washington State Core Indicators Family/Guardian Survey Data

Available online at:

[http://depts.washington.edu/cdpr/docs/FamilyGuardianSurvey\\_Comparisons.pdf](http://depts.washington.edu/cdpr/docs/FamilyGuardianSurvey_Comparisons.pdf)

### **Survey 3:**

Adult Family Survey: Survey Final Report 2001-2002 Data (Phase IV)

Available online at:

[http://www.hsri.org/docs/786\\_P4\\_AFS2002final.pdf](http://www.hsri.org/docs/786_P4_AFS2002final.pdf)

Washington State Core Indicators Family Survey Data

Available online at:

[http://depts.washington.edu/cdpr/docs/FamilySurvey\\_Comparisons.pdf](http://depts.washington.edu/cdpr/docs/FamilySurvey_Comparisons.pdf)



## Panel Members

---

Kathleen Cissell	Bothell, Washington
William Fale	Seattle, Washington
Alison Hahnel	Lynden, Washington
Mike Hatch	Snohomish, Washington
Sherri Huwe	Dayton, Washington
Ken Larson	Bellingham, Washington
Sue Larson	Bellingham, Washington
Meredith Moyer	Lynden, Washington
Noemi Ortega	Pasco, Washington
Christine Rasmussen-Barsanti	Lacey, Washington
Emily Rogers	Seattle, Washington